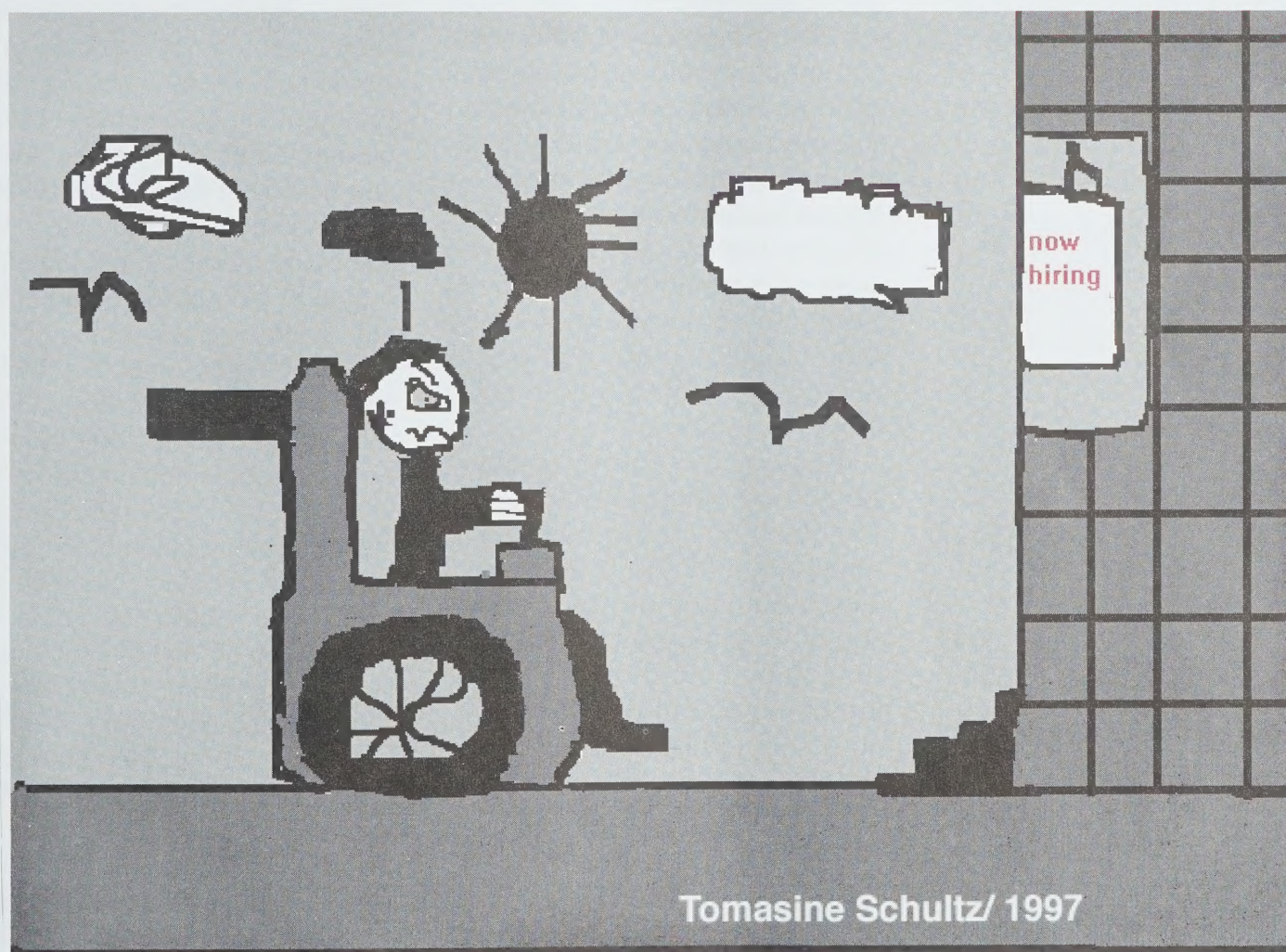


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Employment

SUZANNE CLANCY,
SHIRLEY McNAUGHTON
PETER LINDSAY

Suzanne Clancy is the editor of this issue. She is the founder of the widely acclaimed T.H.A.T. program (Targeting Horizons for Adults in Transition), now in its seventeenth year at Mohawk College in Hamilton, Ontario. Suzanne's special talent lies in her ability to see the untapped potential in others, no matter what their disabilities may be.

From Suzanne

Welcome to the March issue of **Communicating Together**. Several months ago, when I volunteered to coordinate this issue around the theme of employment, I was looking forward to the opportunity to report on the many advances in hiring the job seeker with disabilities. Instead, I am sitting here attempting to write this editorial as I ponder my own potential job loss after twenty-one years teaching in a job readiness program for the employment disadvantaged. The words of Jeremy Rifkin, from his 1995 book *The End of Work*, are ringing in my ears—“We are entering a new phase in world history— one in which fewer and fewer workers will be needed to produce the goods and services for the global population”. He further states that while some job growth will take place in the knowledge sector, it will in no way absorb the vast numbers of displaced workers. Many of my recently laid-off co-workers will attest to that! In the province of Ontario, the current government has nearly crippled the

knowledge sector, through massive funding cuts to schools, colleges, and universities. This has been accompanied by program closures resulting in almost total elimination of support for job training, retraining, apprenticeship, and job creation.

I am not surprised when Tracy Shepherd asks in her article “Where Did Everybody Go?” Tracy, not only do I not see many employees with disabilities, but for the first time in over 10 years, I am seeing very few disabled students in our college. When I questioned this, I was told that provincial cuts have eliminated the funds for anything other than minimal support services, and this cannot provide the level of support needed to attend institutions of higher learning. Students are expected to pay privately for their attendant care, equipment, etc., a rather hard thing to do in the best circumstances, let alone when on a disability pension.

I was also not surprised to read Aleksandar Poposki's article on — *Finding A Job: No Easy Task*. It is to Aleksandar's great credit that he pursued his employment goal in the face of numerous obstacles and finally gained meaningful work. I hope Aleksandar's employer recognizes what a highly motivated, valuable and dedicated worker he has hired. Congratulations Aleksandar!

If Jeremy Rifkin is right, and I strongly suspect he is, then perhaps Paul Marshall, in his article *The Mind-sets of Employment* has foreseen the future more clearly than most. Several years ago when Paul was a student in my program, we had a long discussion over the meaning of work. To Paul “employment is more than getting a paycheck every two weeks”. Paul

gratefully acknowledges that he does receive income support, but I suggest that our Paul and many other “Pauls” earn every penny of this by their contributions to volunteer work, committee work, and any number of other supportive and creative endeavours.

Which brings me to my final thoughts. For two decades I have been a strong advocate of post-secondary education and job readiness training for adults with disabilities. I have had the great pleasure of seeing many of my graduates go on to further education, training or competitive, sheltered or volunteer employment. But I am now seeing the decline of these opportunities for my current students as companies downsize, demand more skill diversity, and lack the time to provide on the job training and support.

Am I discouraged? Yes, often. Are my students discouraged? Yes, sometimes. But together, we are attempting to accommodate to the changing workplace through computer training, more comprehensive work-experience opportunities both within and without the college, and knowledge of “cyberspace” (my students get more e-mail than I do!). Inch by inch, day by day, my “handicapped” students are demonstrating talent, creativity, motivation, and a strong work ethic.

It is incumbent upon those of us working in the field to continue to be strong advocates for the right of those with disabilities to use that talent, creativity, and motivation in a meaningful way. As entrepreneurs in the field of employment for individuals with disabilities, we must continue to develop our own “marketing” skills, working for the day when we no longer have to ask “Where Did Everybody Go?”

From Shirley

Often we are faced with the constraints that a fast-paced society places upon our interactions with those who need our time. Each time we pay tribute to an AAC user whose life has had a profound influence upon others, I think of how much those who take our time give back to us in return! In remembering Chantal Bedard, I recalled the picture of Chantal surrounded by her classmates that we chose for the cover of the *Handbook of Blissymbolics*, published in 1978. Nothing could have been chosen to better represent the dynamic, joyful, labour and time-intensive classroom programs in which children's lives were unfolding with the learning of Bliss. All Chantal's attributes described in the tribute on page 8 were developing as those around her gave their time to her. They were amply repaid in the joy she brought to others.

Like Suzanne, I have turned to the thinking of Jeremy Rifkin in trying to make sense of a political climate that seems to ignore the human cost that is being imposed on the most vulnerable in our society as governments attempt to come to terms with living within their means. I have always recognized how working with those with severe speech and physical limitations sensitizes me to the subtle aspects of communication, human worth and the joy to be derived from simple things. Now I realize how much these individuals also contribute to my goals for society. Of course we must work to reduce a deficit that has been allowed to grow out of control and of course we must learn to live within our means. But we must also face the reality of the human resources and human potential that need nurturing if we are to have a society of any value at the end of deficit and debt reduction.

Jeremy Rifkin's identification of the role to be played by the *Third Sector* is such an important contribution! Those who have the privilege first hand of benefitting from the "wealth" to be derived from working with and for others need to focus strongly on changing the current imbalance in society. As the government and market sector vie for their share of society's resources, the volunteer/service sector has to take its place as the third vital participant. We who have the opportunity to look through the "disability lens" need to focus our view on building an awareness and an infrastructure for establishing a balance. Only then can the contributions of those with disabilities be realized. "Weaning the body politic away from a strictly market-centered orientation becomes the pressing task of every nation on earth" (Rifkin, p.238).



*Chantal Bedard, in 1975,
with her classmates*

The personal experiences and observations offered by Colleen Haney and all the contributors to **Communicating Together** provide a glimpse of a world view that values human as well as monetary assets. AAC users and all individuals who transcend their disability are critical role models for the Post-Market Era in which "participation is motivated by service to others and security is viewed in terms of strengthened personal relationships and a sense of grounding in the larger earth community" (Rifkin, p. 246).

From Peter

Notice our new masthead. We are proud to be the first AAC magazine for the AAC community that is on the Internet. You will have to forgive us if we brag about it for the next year or so. Not only will professionals and the families of AAC users have the opportunity to read the issue but we are happy to be able to present AAC issues to the whole Internet community. And consumers who have access to the Internet will be able to read **Communicating Together** independently without barriers to independent access. Those with physical limitations no longer need page turners. Those with vision limitations can take advantage of the features that Rob Haaf has built in to make it possible to use the Internet Explorer to magnify the print. Those with literacy limitations can begin reading our new "paraphrase" section. Nola Millin has agreed to do this beginning with one article for the March issue and expanding the number of articles if readers find it helpful. We thank Rob Haaf not only for making **ComTog-OnLine** possible but for all the features he has built into it to help AAC users.

To subscribe to **ComTog OnLine**, check our Internet site at <http://www.ahs.uwo.ca/orcn/assoc/comtog>. If you have already subscribed to **ComTog OnLine**, be sure that Rob Haaf has your email address. Send it to him at rhaaf@julian.uwo.ca. Rob will provide subscribers with the password for each issue via their email.

Rifkin, J. (1995). *The end of work*. New York: G.P.Putman's Sons.

Are We Making a Difference: AAC-AT, Employment and Life?

COLLEEN HANEY



Colleen Haney

*In an issue which has employment as its theme, Colleen Haney's presentation at the 1995 Pittsburgh Employment Conference sprang to mind immediately for the feature article. We were delighted when Colleen agreed to prepare her presentation for print. Colleen Haney is a speech-language pathologist who, for over a decade, has been involved in making technology work for AAC users. As she explains in her article, her goals are as high for AAC users as they are for herself. Colleen blends a very personal sharing with a broad multi-cultural perspective in her remarks relating to employment for AAC users. In the September, 1993 issue of **Communicating Together** we featured an article by Rick Creech about the first Pittsburgh Employment Conference for AAC Users. Each year the conference becomes bigger (more AAC users participating) and better. We're pleased to be bringing **Communicating Together** readers another glimpse of this worthwhile conference, this time through the ideas of Colleen Haney.*

The Pittsburgh Employment Conference (PEC) is a great event for any consumer, family member or professional interested in employment issues for persons using AAC systems. Held every year for the last four years in Pittsburgh, Pennsylvania, the PEC provides a forum for consumers to lead the way, to speak their minds, and to give and receive advice and information from successful peers. It's one of the few conferences dedicated entirely to consumers. Over 75% of presenters are Augmentative and Alternative Communication-Assistive Technology (AAC-AT) consumers. It is an event where you can see and hear over 40 consumers with a variety of communication systems interacting with each other and with other participants.

I became involved with the PEC over five years ago through an organization called *SHOUT — Sharing Helps Others Understand Technology*. It includes business professionals, educators, rehabilitation counsellors and consumers, and its mission is to educate others about technology and to help consumers prepare for the job market. Being active at a national level, I was asked by SHOUT to address the conference participants regarding my impressions of employment issues for AAC-AT consumers. The following is a synopsis of my presentation regarding employment issues and questions everyone involved in AAC-AT should ask themselves: "Are we really making a difference in the employment and lives of AAC-AT users?"

Many people are working very hard. A great deal of money is being spent on equipment, therapy, and training. Everyone is busy. Hundreds of things are happening everyday for consumers who use AAC-AT. But are the things that are happening making a difference? Here's a self quiz based on my 11-point criteria.

#1: We are making a difference when we encourage each other never to take "no" for an answer.

I believe we are making a difference when we support each other with the courage and persistence to continue our request until we hear yes. When is the last time you encouraged someone or fostered persistence? I often hear of professionals and families who provide support in the beginning stages of AAC-AT use. But does it continue over the months or years of a consumer's life? Do we help each other connect to mentors or "cheerleaders" who can also give that reinforcement and support when things take so long? Telephones, letters, Internet and e-mail provide us with easy and inexpensive tools to check on each other and to monitor progress and attitude or to send words of experience or advice to others on this journey. How many people do you correspond with to offer support, cheer or encouragement? Are you someone's champion? Have you found your own personal "champion"?

#2: It is not just a job we are talking about — it is a vocation, a passion.

The former Pennsylvania Director of Special Education, Dr. Jim

Tucker, once said to me, “ You really take your job seriously. You work very hard.” I replied adamantly that this wasn’t my job! It was my vocation, my passion. This is # 2. It is not just a job we’re talking about. It is a vocation, a passionate desire to create, to be, to make. Have we helped someone find their passion or explore their purpose for being? Have we realized that we each have a purpose for being? Do we know our own passion, vocation and reason for being? Life is an exploration. We all deserve the right, the tools and the skills to explore the options of life, to find our purpose, our vocation — what we are called to be.

As service providers, as consumers, as friends, as human beings who care about one another, we need to help, to encourage and to support each other to live our passions and to become what we know is in our hearts. Are we helping to develop artists, musicians, writers, actors and models as well as computer workers, teachers, social workers and data entry personnel? Have we really studied the theories of multiple intelligences, or searched for the talents, abilities and skills that may be hidden, frozen or in an embryo state? When have we tried something entirely new or different or so unlike our personality? Do we allow ourselves to stretch mentally, emotionally and intellectually on a regular basis, to awaken our passion, to find our vocation?

I would like to thank all persons with severe communication disabilities that I have met. Without you, I wouldn’t be employed. Now that may sound odd, thanking you for having a severe disability. But in reality, your disability provided me with employment. I, in turn, provide

service. Perhaps I am dependent on you. Does that sound like some kind of exchange theory or reciprocity going on here? Or perhaps some sort of interdependence?

#3: Have we helped each other recognize that interdependence is the key to happy lives?

Question #3 from the criteria list asks if we have helped each other recognize that interdependence is the key to happy lives. Development and dependence in and on our social networks is necessary and healthy to our ecology as a human social system. Are we creating social systems as well as vocabulary or communication competence? With whom do we have interdependent, healthy relationships?

Let me share a few things that impacted my life in the last three years. In August of 1994, I left Pennsylvania to begin doctoral studies and research at Purdue University. This adventure has provided me with opportunities to explore sociology, anthropology, gerontology and multicultural issues. I also work part time with a wonderful group of colleagues and consumers at United Cerebral Palsy of Greater Chicago, (UCPA). Our program at UCPA has the ultimate goal of inclusion in community and employment for all consumers. Every day these issues ring in my head for the over 200 consumers of UCPA services. I travel two or three times a year to Costa Rica, Latin America, where I study Spanish and experience another culture. I teach AAC-AT classes to North Americans and Latin Americans, and am working to develop an international exchange program between Costa Rica, Purdue University and UCPA. I share this because my life has been an odyssey and bombardment and a

constant reminder that there is a “bigger picture” for all of our lives, and for our social interdependence on each other.

4: Recognize the bigger picture.

Have we recognized the “ bigger picture” ? Are we instilling in each other the fact that we are still pioneers clearing the way along the continuum of a better life for each other? Sometimes we get discouraged, frightened, angry, or hurt. We need to remember there is always a bigger picture. We need to keep the perspective from where we came and to where we are going. This tiny moment, disappointment, or delay is only a speck in a much larger picture of our lives.

We all recognize that life is a bigger picture than just “employment”. Employment is an important piece of that picture. But we need to be careful if we seem to judge or set the goal of success solely in terms of employment. One of my colleagues (Terry Willard) suggests: “The only true test of AAC is acceptance in employment.” Rick Creech’s ten reasons to work include “work is an essential part of self worth. I work, I am productive, therefore I have value.” High on the list of factors that determine if an individual is accepted and valued by others is their work status. Others often mention self-esteem and self-image as being tied to work. I would like to remind you however of our cultural biases, that much of the productive, employment value, self esteem, independence data we hear and quote so often is “Anglo-American” or “Euro-American”. It does not reflect the values of other cultures in other parts of the world.

As I mentioned earlier, I often experience a different culture and social group that never asks me what I do for a living, what is my profession or do I have a job. I am recognized, accepted and valued simply for being Colleen.

5: Have we helped each other see that our Euro American value system is not the only one?

Have we helped each other see that our Euro-American value system is not the only one, that perhaps we can gain insight into the value of all persons by exploring other reasons why someone may be valued or have worth? Are we helping each other develop self worth and self esteem by criteria other than performance? I'm not suggesting that we don't need to work. What I am saying is that if you are not working or don't have a job, you are not a failure or worthless. You still have value and great worth to our society and culture. Don't ever forget that!

Few of you may know that several years ago, I had a physical disability and didn't work for over 6 months. During that time, when I visited doctors, filled out medical forms or talked to medical services, I was always asked "my profession" and "what was my work phone number." In fact, several times I felt a real inferiority complex because I left those two spaces empty on medical forms. At this particular time I didn't have a work phone because I spent the majority of time at home in bed. My job during this time, my life's work for this period, was to get well. It took all my energies. I found myself asking myself questions like — "If I could never work again would people devalue me? Would I lose my

friends? Would people think I was incompetent because I wasn't working?" I can obsess with the best of you!

I also found that during this time, I had to talk about different things with my colleagues because I didn't have work experiences to share. When I did talk to my friends from work, it only took a few weeks before our conversation time diminished because we no longer had common communication topics.

So where is all this leading? I believe there are ways and means other than work to have value and worth in our society.

What I am saying is that if you are not working or don't have a job, you are not a failure or worthless. You still have value and great worth to our society and culture.

6: Have we helped each other see our value and worth through many examples of being?

Have we helped each other see through many examples of "beingness" so that no one item determines a person's value or worth. How about this paradigm? Because I have value and worth, I chose to work and share my value and worth with others.

In Central America, I was so critical and judgmental when I saw people gathering together to just sit and talk on the porch. "What wasted time" I thought! By the end of my first stay there however, I knew it was a "gift" to spend time just talking to someone with no other agenda. I read an article a

few months ago that stated our society is becoming so busy, so fast paced, and so connected to technology, that we have lost the true connection to each other. People now need to create *conversation groups*: once a week people get together to sit face to face to just talk to each other!

7: Have we helped each other develop good face to face communication skills?

How good are we as communicators? I personally believe you can talk your way into anything. Actually, it is marketing. Have we helped each other develop these skills to market ourselves effectively or to talk an employer into hiring you?

A review of many gerontology studies suggests that a critical issue as we age becomes the social support systems that we have developed through our lives. What is important is people connecting with people, friendships, someone stopping by and chatting, someone to sit on the porch with you, someone reaching out to touch you.

#8: Have we helped each other develop and expand inter-generational social support systems beyond the family.

Have we helped develop communication skills that include calling a friend, sending cards to friends, knowing ways to prolong your interactions with others, knowing how to communicate compassion, sympathy and caring in reciprocal interactions. The term "Fictive Kin" has developed to describe significant non biological persons we adopt into our lives to be there for us and likewise, be there for them. In a practical sense, have we helped each other develop skills to network, develop other "kin" or "work a room" (i.e. when one circulates at a business meeting or social function to

make as many contacts as possible)? How many of you collect or exchange business cards on a regular basis with new acquaintances? Do you even have a business or address card readily available to exchange? How many potential new friends do you let slip past you each day? You have so much to offer others and each one also has a gift for you.

#10: Have we helped each other develop the courage to take risks?

Randy Kirsh and Michael Williams of California, Jim Prentice and Rick Creech of Pennsylvania, and many others shared at PEC the risks they took in their search for employment. Eventually the results came but only after they showed the courage to step out and put themselves on the line.

11: Have we done our homework?

The last criterion calls for serious job hunting, carving, creating, whatever you want to call it. What I am suggesting calls for a refocusing and shifting of our paradigm. People discussing employment talk about "getting people jobs" or "fitting them to jobs". In today's world of high technology, money is getting tighter, companies are down sizing, right sizing, or buying each other out. This is not a "user friendly" time to help anyone get out there and find a job. Our world is rapidly changing and so are we. As we change, our needs change. Our needs for products and services are changing daily and the consumers of all products and services are changing too. What are we doing to anticipate this?

Maybe we need a new paradigm. Maybe we have to believe that we can develop or create new services

and products ourselves. Maybe we don't need to fit into corporate North America. Perhaps we can make a new way. How are we preparing the people we work with for this? Are we aware of the changing American demographic? Have we been watching the trends? How have we helped consumers use their passion to make themselves self supporting to provide services or products in the global market? We need to develop creative "think tanks" to ponder the changing world of global consumers. We need to think creatively about what new jobs, services, or products we can deliver to our increasing multicultural populations in North America, to the largest growing population of consumers in history — baby boomers over 45. What will women, who will live the longest and therefore be the consumer retained the longest, need in the next few years? What do women need now? We need to develop ways of providing necessary and important products and services to these populations. We need partnerships with retired or furloughed former chief executive officers (CEOs). We need to identify the services or products that will facilitate intergenerational interaction. This is important since we see two groups of people growing rapidly — the young and the old. There is so much to do to plan these think tanks, to organize marketing seminars for consumers, to help consumers think about their skills and abilities to be entrepreneurs. How about conference sessions or workshops on "developing your entrepreneurial role in business"? How about workshops on creating your own video résumé?

Consulting and contract work is the work of the future. How can we help you package your educational

workshop, market your seminar or break into the lecture circuit?

And while we are at it, how many of you will make a commitment right this moment, if you are employed, to contact your business' or company's or school's human resource person or CEO to plan a meeting to discuss some of these issues?

Advocates, mentors, leaders, supporters, visionaries, organizers and if needed, revolutionaries are here in our midst in the field of AAC-AT. They are ready to do whatever it takes to continue to make a difference in constant evolution to make people's lives better. Can you identify any of them? Do you have a way to contact them? Take a risk and get involved!

According to my criteria, as yet we don't have a perfect score for making differences in AAC-AT, the employment scene or in people's lives. I believe, however, that we collect extra points when we've ignited the spark of creativity and determination in another. In spite of the fears and concerns over changing governmental policies, funding and economic downsizing, I think we can do anything we set our minds and energy to do! I hope many of you will make plans to visit the PEC conference in Pittsburgh, Pennsylvania on August 8-10, 1997. We'll continue this topic and learn much more!

Additional information about PEC can be obtained by calling 1-800-934-4391 or via email at:

"SHOUT9666@aol.com".

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Remembering Chantal Bedard

*"Weeping may endure for a night,
but joy cometh in the morning."*

Psalms 30:5

One dreary day in the middle of December, I felt compelled to take a short drive in the car and ended up in the village of Morrisburg, where I bought the last *Ottawa Citizen* on the store counter. That day, December 15th, I had a very bad feeling that something awful was going to happen. Back home, I rapidly thumbed through the paper until I came to the death notice for Chantal Bedard.

Some people come into our lives and touch us in such a way that we are never the same. For me, Chantal was like that. Although I was her teacher, it was she who taught me.

When I first began working with her, she immediately sensed my fear and uncertainty about working with her disabilities. Her own sense of tranquillity and patient equanimity calmed me. I was struck by the intelligence reflected in those large liquid eyes of hers, eyes that spoke so much without words, eyes that laughed mischievously and sparkled with shared amusements, eyes that reflected my own soul. Her beautiful eyes too often mirrored the pain of the muscle spasms in her arms, the chaffing discomforts of her wheelchair, and the frustrations of being unable to communicate verbally. Chantal talked with her eyes. Even without her voice, she was a powerful communicator. Chantal was laughter — who can forget that deep, throaty chuckle which so often rippled through our classroom?

As a student, Chantal impressed me with her lively intelligence, her willingness to work hard and eagerness to learn, her drive to succeed, her ability to organize her work, her patient determination to do well everything she touched.

As a woman, Chantal deeply loved her very special male friend. The special glow in her eyes when his name was mentioned could light up the darkest night. As a woman, Chantal had the hopes and dreams of any young woman who loves. It gives me some peace of mind to know he was by her hospital bedside during what was to be her final struggle.

Chantal was a unique human being. I will remember most her courage, her personal and work ethics, the way she treated people. Everyone loved Chantal. Perhaps it was because Chantal had "personality plus". And she was so much fun to talk to and be with. After she taught me how to use her colour-letter board and Bliss symbols and I felt more comfortable with these, we could communicate well and — she loved to talk! Fashion, music, men, favourite colours, books she had read, her wild "Hollywood" sun glasses, life — there was so much to discover about her. Chantal made the most of her short life — and lived each day to its fullest.

On earth, a light has gone out and her name was Chantal. In heaven, a bright star shines forever and her name is . . . Peace.

Linda Anderson

§

Chantal was my girlfriend. We met at a treatment centre when I was 4 years old. We went on trips together to Disney World and Toronto.

Chantal and I often went together for respite care at the Rotary Home. We were able to talk together without our families. We both used our Voice Synthesizers. On my 21st birthday, Chantal and I went to the Olive Garden with other friends. We told many funny stories and laughed a lot. When the bus driver picked us up to go home, he took Chantal to her family's apartment instead of the Rotary Home. We frantically tried to get across to the bus driver that she was going to the Rotary Home. We laughed all the way back.

Chantal and I also went to work at Computer Wise when we finished at McArthur High School. Unfortunately however, Chantal and I could no longer go to the Rotary Home for respite care when we became adults. The Rotary Home is only for children.

On September 31, 1995, Chantal went to the Elizabeth Bruyere for respite. There she became very sick and was admitted to the Ottawa General Hospital. On October 4th she was put on respirator. Later on she went into a coma for 6 days and caught pneumonia.

I thought I would not be allowed to see her there in the intensive care unit. I thought I would try anyway. I was very surprised when they let me in. I talked to her for an hour and I kept going to see her every Wednesday morning. I would tell her about the news at work. I talked about many things. I felt that she could hear me.

I went to see her on a Tuesday. Little did I know that it would be the last time that I would see her. I was

afraid that she might die. Thursday I got to work and got the news that she had died December 13, 1995. I felt very sad but I was thankful that I had seen her the day before. I had to go to a meeting at Algonquin College Thursday afternoon. I could not think very well I was so sad.

Friday afternoon I went to her wake. I said my last goodbye to her. I went to her funeral on Saturday. I knew her for most of my life.

I miss her. **Jorge Almeida**



**Chantal talked
with her eyes...
eyes that spoke so much
without words.**

The first time I met Chantal it was in school. I thought "Wow she is really complicated." But after I got to know her, I could communicate with her. I was really proud to know Chantal because she was a fighter in many different ways. I mean Chantal wouldn't give up. If she wanted something she would try to do it.

I do remember when she got a new voice machine. That day was really exciting for her because finally she was able to communicate on her own. Before Chantal had a

book with many different words. Someone had to hold up that book in front of her and she pointed at the book with her eyes. As her teacher Linda Anderson said she was able to communicate so much with her eyes.

Oh yes, Chantal loved to talk. She also really loved to eat. I remember when Chantal was in pain she laughed. I asked her why do you laugh when you have pain. Chantal told me that she didn't want to cry that was why she laughed. Chantal liked the soap opera *The Young and the Restless*. We had good talks and some laughs about it.

One important thing about Chantal was that she wanted to find a home for herself because she knew that her parents were getting older. She wrote many letters to politicians and government officials to ask to help her to get a home. But Chantal didn't get the home she was fighting for before she passed away.

Chantal had a lovely family who cared for her and who stood beside her all the way.

Treena Guy

I remember once Chantal came to visit me. She was staying at the Rotary Home to give her family time off. The Rotary Home is very close to where I live.

Chantal loved going there but later she couldn't go anymore. It is a relief home for children. There is not any special relief home for adults. It is too bad. Chantal had to go to the hospital to give her parents time off. Jorge had to go to the hospital too. I think that is very bad. I don't know why they did not think about that before.

Justin Clark

Where Did Everybody Go?

TRACY SHEPHERD



Tracy Shepherd

Take a look around you in the workplace. Do you see many minorities in colour, race or disability? Not many! Specifically, do you see many individuals with any sort of disability — perhaps a few with a hearing impairment or slight visual problems, or the occasional person with a physical disability who requires some adaptations in the environment to perform the job? Do you see anyone with a speech impairment? I could not find anyone in my community who was nonspeaking and gainfully employed.

Working at treatment centres we see a great many children. We train them in such skills as directing their own care. We devise innovative and unique communication systems for those who are nonspeaking. We often see these individuals into their later teens or early twenties. But then where do they go? It is a difficult subject to broach with parents who are at varying stages of grieving. At what age do we ask the dreaded question, "What do you see your child doing when he or she is finished school?" Realistically the planning for job placements should begin really early while they are still in

school. Often such things as schedules for therapy and assessments for wheelchairs and Hart walkers and communication devices and health concerns get in the way of starting to think about employment.

At what age do we ask the dreaded question, 'What do you see your child doing when he or she is finished school?'

Job Shadowing

There is an interesting program in Essex County that I discovered in preparation to write this article. It is called *Job Shadowing*. It is designed to provide individuals with disabilities the opportunity to follow a person in a position that interests them in hopes that it will lead to employment. The program is run by Neil McTavish and a group of volunteers at a Windsor outreach community organization. The coordinator of the program explains that they don't guarantee jobs at the conclusion of the program. As well as providing an opportunity to shadow a job that clients find interesting, the program also teaches some prerequisite skills needed for ultimately achieving employment. The program has contacts at approximately 40 different employers in the area varying from Burger King to Hiram Walker. They provide workshops that train individuals on how to write a cover letter and résumé. The job shadow itself runs for one day and a half. They have people in the program of all ages with varying levels of education. All of the clients have a disability of some type.

In order to place the clients, they each come in for a day of interviews with 10 different employers and a

placement is determined. Neil explained that nearly all clients who were interviewed obtained job shadow placements. Those who didn't, required further work in aspects of professional conduct or did not take the interview seriously.

During the day and a half job shadow, the client is allowed the opportunity to follow around an employee for the day to ask questions and to determine if this is a job they could see themselves doing. The program is outstanding and requires much time and planning. Neil explained that they had not placed any nonspeaking individuals that he could recall. In fact, the overall percentage of clients who obtain employment following the job placements is unfortunately small. Of the 84 job shadow placements last year, Neil reported that only 2 or 3 were successful in gaining employment. We hope there will be more in the future.

You heard from David Dame in the December issue of **Communicating Together**. He had the opportunity to job shadow before getting hired at his current position. David explained to me that the job shadowing alone did not get him the job. It was his persistence and selling himself to his employer by volunteering his time and taking on extra jobs that eventually got him a *paying* position. David is now working hard and loving every minute of it. At the ripe old age of twenty six, he has been able to purchase an accessible van and is in the process of looking for a house to buy. Good for you David. Keep up the great work!

The Co-op program

Another program which can help young people increase their job training as well as expand community

awareness of the needs of students with disabilities is the high school co-operative program. Students from various high schools are allowed the opportunity to work in a selected work place for a semester, usually in grade twelve. The goals of the program include job readiness training. In just a few weeks, our centre will have a co-op student from a local high school who is quite unique. He has cerebral palsy and a speech impairment. Aleks is a client of ours. Each summer, he asks for our permission to include our names as references for his résumé. I

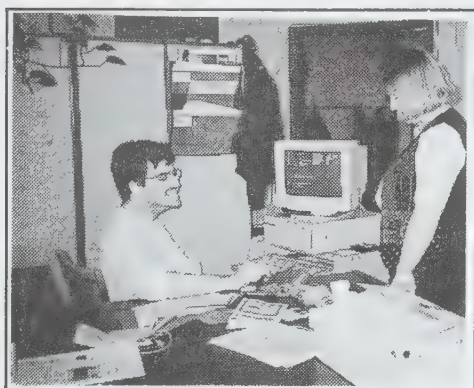
don't believe he has been very successful in gaining summer work. Why? As you will see below, Aleks is a computer wiz. Our centre has various computer tasks for him to complete during his co-op stay with us and we will provide him with training in the basic skills one needs to gain employment. Since he is very knowledgeable about the EZkeys method of rate enhancement and voice output, he will be a great asset in setting up and training individuals who are using those types of systems. I am sure the sky will be the limit for Aleks. If any

workplace is able to give Aleks a valuable work experience shouldn't it be a rehabilitation centre? We can only hope that after his experience he will be able to gain employment in the community. Aleks has written the following article outlining how, for him, finding a job is "no easy task". Perhaps at the conclusion of his co-op placement, he can share with us his thoughts about the benefits and drawbacks of his placement at the Children's Rehabilitation Centre.

§

Finding a Job - No Easy Task

ALEKSANDAR POPOSKI



Aleksandar talking to a work colleague

There comes a time when a teenager feels that his allowance is just not enough or that he has too much time on his hands. So he looks for a job. In today's society, many teenagers and grownups, educated or not can't even find a simple part-time job. Not to mention the "perfect job", if there is such a thing!

Tragically, it seems like it is the less educated people who are able to find a job faster and sometimes even better than the more educated individual. I have a friend who went to school for nearly eighteen years. She got a master's degree in criminology. After six months of search however, she was barely able to find a job and the one she did find was 500 kilometers away from her home.

Another example is Windsor's "Big Three" automobile plants (Chrysler, Ford and General Motors). There are a lot of doctors and lawyers working on their production lines.

For me, a physically challenged seventeen-year old individual, it is much harder to find a job than for a non-disabled peer even though the peer may not have as much skill and enthusiasm. I feel I have great skills in computers, and understand more about how the computer functions than my friends, who are also very interested in computers. I have expressed my knowledge many times among friends and teachers. Once, two months ago for example, a teacher asked me to set up a dual function operating system on his computer (Windows 3.11 working under Windows 95). When I finished, he didn't know what to say. When I told a computer engineer what I'd done, he said "*That's impossible!*"

The same teacher told me that he knew someone who had a steady, well paid computer job but who didn't know as much about computers as I do. He also encouraged me to take Microsoft, Novell, and other certified training courses but I've put that idea on hold, at least until the summer. I think that my co-op work at the Children's Rehabilitation

Centre will be a good experience for me. I believe that it might help me with a job, as well as increase my personal knowledge.

Nearly a year ago, my brother and I decided to open a home based business called "Mace Computers". It's not like we're making money. Our record so far is three customers a month. I like to look at it as a part-time hobby as well as an opportunity to gain some more experience and knowledge.

Many times I've helped some friends with their computers. Mostly, if the job is minor, I don't charge them because I believe that friendship is worth more than money. I sat down with another friend who did not know too much about computers and put together a fully functional computer for him. At first we were scared. It took us three hours to do but we were pleasantly surprised when it all worked. When we were done, I realized that it wasn't as hard as I had imagined. Since then, I've put another computer together myself using an electric screw driver. I have also worked on several with my brother. Those seem to go a little faster — one hour was our record.

I am looking forward to my co-operative work at the Children's Rehabilitation Centre where I hope to further my knowledge and experience.

§

The Rainbow Programs — Choices, Independence and Freedom

MADELENE LEVY

Madelene Levy has taught for many years in special education classrooms, helping young people and adults with disabilities develop their academic skills. Now, Madelene is applying the knowledge she has gained over the years to a new way of teaching. Her Rainbow Programs are a wonderful example of a teacher taking the initiative to create new educational opportunities as established programs are cut back. It is interesting to note that Madelene doesn't specifically describe her teaching of AAC users in her article. We know they are among her clients. We also know that because Madelene is so comfortable communicating with them, she doesn't think to mention the fact that they don't use speech as their way of communicating! After all, she personalizes her teaching, so it's just one more dimension to consider.

My name is Madelene Levy. I design and deliver customized programs which help adults with special needs to have more control over their daily living. I offer people choices, independence and freedom in ways that were not available to them before. I am not a psychiatrist, psychologist, social worker or therapist, all of whom I hold in high regard and work closely with. I am an educator with 20 years of experi-

ence. My background has helped me to develop some new ideas which enable people to become more independent and happy.

Before I tell you more about these ideas however, let's discuss the environment we find ourselves in today. As we all know, due to funding constraints, boards of education are being forced to cut back on their support for adult education programs for those with special needs. In fact, government funding for programs is coming under closer scrutiny than ever before. In many cases, they are either being reduced or totally eliminated. Too many programs are chasing too few dollars and it is not going to get any easier in the foreseeable future.

I know of one program that once served 42 adults with disabilities, ranging in ability from pre-readers to grade 12. When funding for this program was transferred from the local board of education to a government agency, the teachers were informed that some of the clients did not fit the government's mandate. The numbers were cut from 42 to 32 and the full week was cut to 3 days. Thus the transfer resulted in a cutback of 25% in the number of people being served and 40% reduction in resources to serve them. It is obvious that we are talking about a drop in both the quantity and quality of service. This is not an isolated incident. It is being repeated around the province, in fact around the world every day.

Given the drastic cutbacks in programs for adults, what will happen to an individual after he or she leaves high school? Perhaps a fortunate few move on to special

needs literacy programs at community colleges. But there is very little in the way of programs that focus on independent living, geared specifically to the needs of the non-reader or limited reader. Should this stop them from living on their own, making personal choices and achieving a working degree of independence? Of course not. We have to find more creative, resourceful, non-traditional ways to help some people with the task of coping with the basic challenges of daily living. This is where I can help.

The Rainbow Programs

For a number of years now I have been developing the *Rainbow Programs*. My clients live in their own apartments, in group homes or with their parents. They are often in some kind of work placement but may have limited or non-existent reading skills. They typically want to maintain their independence but may be challenged by simple tasks such as shopping, cooking and basic nutrition. They have often attended conventional training programs in these areas, which for one reason or another have been unsuccessful. Under the heading of *The Rainbow Programs*, I currently offer customized programs in nutrition and meal planning as well as in money management. Other programs are in development.

How do you teach a non-reader the concepts of food groups, portion sizes and how to plan a weekly menu and complete a shopping list? One answer is the nutrition and meal planning program I have developed. It consists of five lessons based on the Canada Food Guide. By making extensive use of computer-designed,

colour-coded materials and incorporating pictograms widely, the client is able to learn the concepts quickly and easily, regardless of reading ability. The program is taught in familiar surroundings such as their own apartment, group home or in the family home where the client is most comfortable. The program can also prepare them to move into their own home. A variety of creative teaching approaches such as card games are used to make the learning experience motivating and fun. Every client receives his or her own customized package which takes into consideration allergies, personal tastes and dietary needs. The typical package includes, among other things, a flexible reusable weekly menu planner and a personalized shopping list. To teach appropriate shopping habits in their own communities, I take them on shopping trips to their local supermarkets or stores. My other courses to support independent living use similar concepts and techniques.

Outcomes

Let me share with you some of the outcomes and the reactions of the clients I have been working with. One of my clients for example is a diabetic and non-reader. She was unable to understand the diabetic food portion charts. I developed a customized pictographic food portions communication book and provided her with colour-coded measuring cups. This enabled her to quickly learn and understand the process so that she could take control of her daily food portion intake. I have also been called in by a care-giver when a client was in danger of losing their independence due to an inability to master basic living skills. Another client was a non-reader, living with five other non-readers in a group home. I designed a package

of personalized pictographic menus and shopping lists for her. This work so impressed her worker that he implemented it for the entire group home. Previously, none of the residents had any idea of their menus for the week even though the menus were posted. The menus were written but the residents did not read. The menu display was for the parents rather than the residents. The aids for meal preparation and shopping have now become key parts of my client's preparation for moving out into her own apartment.

Should being illiterate stop individuals from living on their own, making personal choices and achieving a working degree of independence? Of course not!

The key to success in all of these situations is providing clients with personalized tools in a positive, non-threatening and stimulating way. The skills developed can then be used independently when the program is finished and the consultant is no longer available. An essential success factor is the willingness of the care-giver to support the client and the program and to continue on with its principles once the consultant has left.

The Rainbow Programs also provides peace of mind to the parents of my clients. They are reassured that if anything happens to them, their child has some independent skills with which to survive. The programs also provide valuable support for other care-givers and professionals working with the clients. The following is some of the very gratifying feedback that I have received from both my clients and their circles of support:

From a client: "Why was I not given this kind of shopping list before? Now I can shop on my own and I know what to buy." From the parent of a schizophrenic client: "The one-to-one approach has given this person a much more positive outlook about himself." From a care-giver; "They would never have continued a course that they would have had to leave home to go to. They enjoy your coming in."

Other Issues

In developing a program of this type, a number of practical issues need to be considered. I go to the client for example. Thus no bussing is required. In addition, the expense of providing for an accompanying care-giver or aid is eliminated. And the Rainbow Programs have never been canceled due to bad weather (a tribute as much to my trusty Honda Civic as to me!). Also, it is sometimes beneficial to bring a neutral third party into difficult situations. Developing a relationship based on trust and respect, but separate from parental duties, can result in a success that others, too close to the situation, may have failed to achieve.

These programs are designed to provide the tools which help develop independence, which in turn encourages people to become functioning and capable members of the community. The result is increased self-confidence, knowledge and control. In short, I help people realize they have choices, independence and freedom.

For further details about the Rainbow Program, Madelene Levy invites you to contact her at 905-642-3204.

§

KARI HARRINGTON



Kari Harrington

*We are delighted to have Kari Harrington once again contributing to **Communicating Together**. Many of you will remember that Kari was the Associate Editor for a column on "Living" for a number of years. Kari has now joined the information revolution and can be reached by email at "harring@istar.ca". Send her a note. She can of course still be reached though writing to **Communicating Together** as well.*

Do you remember my last regular column article, "Once Positive, Now Discouraged" (Vol. 12, No. 1/March '94)? Well I became even more depressed. I was having a lot of discomfort from my hip which made me have more seizures. Therefore, I did nothing except drive around the

building in my wheelchair and beg Kathy, my support worker at the Participation House(PH) in Markham where I live, to get me out of my chair and onto the mat.

A few years ago, I vowed that I wouldn't let myself get very depressed like some people do. But here I was heading for depression. This thought was very upsetting to me. I talked to Kathy about it and I told her that I didn't know what happened to the real Kari Harrington. In my mind, the Kari I knew had disappeared. We talked about what was different between now and before my brain surgery. After we talked a bit, Kathy said she had a couple of ideas. She would make a few phone calls. I didn't know what Kathy had in store for me.

A few months later Kathy told me about a program they had at the Aphasia Centre in Stouffville. As Kathy was talking about it, I was thinking, "What am I getting into now?" At the same time however, it sounded very interesting. Before long I had an interview with the program support worker. The interview went very well. I learned that aphasia is the loss of communication caused by a stroke or a head-injury. I also learned how aphasia is different from cerebral palsy when it comes to speaking, listening, reading and writing. I thought because both our brains were damaged, the speaking, listening, reading and writing processes were the same. People with aphasia need key words written down, gestures, pictures or the real object to help them understand what we are talking about. The volunteer aphasia program has six groups with two volunteers at each table. This made me feel comfortable knowing

that I didn't have to do everything. It was going to be very challenging for me. They group the clients by their interests which is a good way. After watching a video about aphasia, the program support worker gave me a lot to read. She told me that I could start the next Thursday afternoon, which both of us decided was the best time for me.

Kathy took and picked me up the first time and then arranged for the Markham mobility bus to take me every week. Going to work on the mobility bus would give me some freedom. I was taking my lunch. The bus picked me up at twenty to twelve. Sometimes I wonder what some of these drivers are thinking. I often came home in a taxi that was supposed to carry only one wheelchair. My big electric wheelchair barely fit in. Twice however, the taxi driver tried to take two people both of whom had electric wheelchairs. They put me in and they thought they could put the other chair in the back. The person got out of it and sat on the seat. Can you imagine lifting an electric chair with batteries and all? It ended up that I got out and the program support worker phoned P.H. to pick me up. After going through this twice, the people at the mobility bus said they couldn't promise a big bus every time. I go in the P.H. van now. One good thing about going by the P.H. van is that I can eat lunch before I go. By this time, I had a problem swallowing so I only took an Ensure pudding and drink. When I started to eat at P.H., I felt much better.

When I get to the aphasia program, we have a meeting before the program starts. In this meeting we find out which group we are assigned to, discuss what we are going

to do that day and what topics we are going to talk about in the groups. When the program starts, we first do movements to music. Then we have discussions. Some topics were about spring and flowers and some about the summer olympics. We always find topics from looking through the newspaper. This is where we write down key words, gesture, draw pictures, or use pictures in newspapers and books in order to communicate. To show where a place is, we use maps or the globe. For the people who can't talk at all, they put their thumb up for yes and down for no. We write choices for them to point to. This not only helps them, it also helps me to hear everything as I have a hearing impairment. Then we have a coffee break.

After the coffee break, we have a choice of art, music or crafts. These happen on successive months — art one month, music another month and the same with crafts. Alternatively, participants work on the computer or continue with discussions. The program ends at three-thirty. After that, the volunteers have their pro-

gram meeting where we discussed how things went, what problems we had and what we could do to make it better.

When the program ended for the summer, we celebrated at the Timber Golf Course. This was nice because it was the first time my parents met the people I work with. We played golf. Although it was hard for me to play, I still had fun.

When the program started up again in September, it changed. For the first half, there are now three groups — an art and games group, a writing and story telling group, and supported volunteer training group for the new volunteers and some of the clients who want to become volunteers themselves. I'm in this latter group. Here we learn what happens to a person's communication skills when they have a stroke. It was very interesting to me to find out that our brain is like a dictionary. With people who have aphasia, the words get re-sorted. We learned how to help them to get the word they want, but also to give them time to find the word themselves. It's better

to speak in short sentences and use short, simple words. We also must make sure they can make eye contact and hear. It's our job to make sure everybody gets involved. If someone seems to be bored with the topic we are talking about, we might ask them to choose another topic. On the other hand, if we have a person in the group that keeps on talking, we have to make sure they let everyone else have a chance to talk. We do this by words or touch. When we are finished with a topic, we have to make sure that everyone knows that we are changing the topic. To do this, we most often draw an "X" through the topic written on the paper.

In the time I have been working at the Aphasia Centre, I have enjoyed it. I have a feeling that I'll enjoy it even more this year as I help the clients to write their stories on the computer and in the group. I'm beginning to see the real Kari Harrington coming alive again, in spite of her problems.

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SHERRI PARKINS

We first came to know Sherri Parkins as a skillful American Sign Language (ASL) interpreter. She then became involved in AAC and developed the same high level of competence with assistive technology. While we were impressed with her mastery of ASL and her later adaptation to both high and low tech, it was her intuitive teaching ability and her caring about the persons with whom she worked that impressed us most. We disagree with Sherri when she claims her CV is not very impressive! We believe she has the most important qualifications of all for teaching adults who use AAC. Sherri believes in her students; she never stops learning herself; she seem to thrive on problem-solving; she analyses where the roadblocks are and takes action; she relates academic learning to everyday life. Her students are lucky indeed. They have a friend, an advocate and a teacher!

When I was persuaded a number of years ago to teach a literacy class of adult students who use AAC, I was introduced into an area where I was totally ignorant. Adult literacy. What did I know about that? I was hired not because of my skills as a teacher but rather because I knew how to talk with "those students". Not a very impressive curriculum vitae. I will say that I have been plunged into an area of education that has so much potential but where so many frustrations block the way.

Technology always seems to be dangling a new carrot in front of our noses only to have it consumed by the realities of budget. I remember my first day at Seneca College. I walked into a lab of twelve 386 computers and thought, "Wow! I have everything!" I guess you could compare that to walking into a car dealership and discovering only too late that if you want more than the engine, you have to pay for it! Scanning access programs were ordered, switches purchased and the task of finding the best word processors tackled. Then there were cables that did not plug into any holes that I could find! I also discovered that I had to learn how to operate the computer. Seven years ago that meant knowing what to do with a computer that looked at you and flashed a not too interesting "C:>" prompt. It is safe to say that the most learning that took place that first year was not in the students that were brave enough to try yet another literacy program. It was in me!

What if?

As I started to learn, I started to dream — *what if?* What if books could be available through the computer? No more need for expensive page turners that don't work or no more waiting for someone to turn the page for you! What if people who had learning disabilities, in addition to their physical disabilities, could learn to access information through the use computers? If they had visual processing difficulties, this could be accomplished through their ears by means of a screen reader. Perhaps intensive exposure to visual information would be the solution if auditory processing was

difficult. What if we could apply technologies we use with the blind to any person who would benefit from their use? What if we all could have access to the Internet so that information is literally at the learner's fingertips? What if everyone had access to the best technology and it never broke down? Today I still am dreaming. I hope that one day the "what if's" will slow down long enough for us to catch up.

I know some professionals might be upset by my seeming abandonment of teaching "traditional" reading. For my students however, the reality is that they will not ever be able to go get a book, sit down, turn pages independently and enjoy the rich worlds that literature can take them into. If we can teach them, however, how to access the information through the use of computers, then they will be able to *listen* to the information as a screen reading program reads the text to them, automatically scrolling through pages and pages of information. Then perhaps I will have opened up a whole new world to them. If they can *communicate* more effectively because they have learned how to use spelling strategies to convey a message, then literacy training is meeting a need. If a prediction program allows them to spell all the words in a theme list without error, then more power to them and to the technology that allows them to succeed. Then literacy training will have served them well.

Some Other Issues

There are other general issues that are raised both in regular adult literacy and in adult literacy programs with learners with disabilities. There are days when literacy

must take a back seat to life issues that need to be dealt with immediately. It has been said that in order to progress one grade level in reading, a person needs one hundred hours of instruction. I think I could count on one hand the days that we have had one hour of uninterrupted instruction.

The other issue that raises itself in the area of adult education is the issue of *choice and relevance*. Adult learners need to have a say in what they want to study and learn. Adult materials must be relevant and stimulating. This is where I wish I had an army of volunteers to search for materials and use scanners, tape recorders, or photocopiers to copy them into formats that are accessible to my students. In grade school, all the children follow a set curriculum. This is not the case in adult education and this fact adds to the enormity of the task.

Another issue for students who use augmentative communication is learning to use their communication systems in an appropriate manner and with the finesse that they desire. Strategies must be learned so that they can respond to new situations. Many of these students have, for the first time, the power of speech that new technologies have introduced. These new technologies require new sociolinguistic skills such as when to speak and when to be quiet and when to listen, when to prepare a message they may have. These skills take practice and time to acquire.

Teaching these more general communication interaction skills is an important part of a literacy class for adults. Although literacy may be the focus, the need for continued communication training does not disappear. The classroom represents a stepping stone between the skills learned during clinic sessions when a new system has been prescribed and

the realities of the real world that they must cope with on a day-to-day basis.

**Literacy can be many things
but at the very least, it is the
doorway to many exciting
new experiences!**

Most instructors of adult literacy are envious of the many learning resources that elementary school students seem to have. Most classrooms today have technology in place waiting to be used to help transform the students into functional adults. The students that I teach through the North York Board of Education's literacy program are a unique group. They are benefiting from the opportunities available to them because of the partnership of the program with Seneca College. The college provides the computers and technical support. This is not true of most adult programs. Even with the technology in place, we seem always to be struggling with keeping up-to-date.

So What is Next?

Where will my students go when they are finished their literacy training? Will they find employment? Will they develop satisfying social lives and acquire the skills they need to be able to live independently? In this current political climate, it is difficult to answer these questions. It is exciting to think about the new doors to society that the Internet could potentially open for them. Where doors to employment seem so firmly closed the Internet may provide other occupations. Perhaps training students in programs that give them the skills to participate in the wealth of opportunities that the "Net" offers would be a worthy task.

One of the biggest problems for adults with severe disabilities is the isolation that they feel. There is a whole world out there for them to discover. Access seems to be the key. Perhaps over the next few years, we will see the focus on literacy for adults with severe disabilities turn more and more to a focus on learning the skills required to participate in this exciting area of the information highway.

Literacy acquisition is not an easy task. Some of my students have worked for 5 years and are still only reading at an elementary school level. But we have improved their skills enough for them to use technology to assist them with their daily lives. Literacy can be many things but at the very least, it is the doorway to many exciting new experiences!

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A LIFETIME OF WORKING AND LEARNING

An discussion between Steven Hanlon and Alda Steprans

For those who acquire a communication impairment through Huntington's disease, many other changes enter their lives. We are always indebted to Alda Steprans for her sharing of the quiet times she spends with her patients. This discussion between Steven and Alda is edited from a series of discussions the two of them have had on the topic of work.

Steven, you told me that you used to work for American Motors. Why did you stop working there?

I was laid off because of a lack of work. Then I worked as a shipper at Sears. My mother worked there and she got me the job. I liked working there, but again, was laid off because there was not enough work. Then I worked as a shipper for a couple of years. I was laid off because I was too slow.

Did you know you had Huntington's disease then?

No, I was not diagnosed, yet.

How did it make you feel to be laid off because you were slow?

I was angry and felt hurt. My wife felt awful, too. Then, I went to school at Humber College and studied air conditioning. I did not finish. I failed the subject. It was only after that I found out that I had Huntington's disease.

What did you miss most when you stopped working?

I missed the work. I missed the pay.

Were there any advantages or benefits to not working?

I can't think of any.

Do you think you learn or work here in the hospital?

I work in physiotherapy where I practice walking. My work at the computer is important. It is great! I have learned to use the computer here. I play games. In speech therapy I practise talking clearly.

I notice that you are speaking more clearly this time.

I have also learned how great it is to eat.

I remember from your last interview that you have always enjoyed eating.

Yes. I can eat the food here. I have gained 10 pounds since I have been here living in the hospital.

Would you like to work more?

Yes.

What prevents you from working more?

I do not have enough time. It takes longer for me to do everything. Eating takes a very long time.

I have noticed, Steven, that you always show up for the therapies here. You are very responsible about learning. Why is that?

I like it. I am not rushed here. I like that, too.

Have you considered that you also teach others here?

No.

I have certainly learned a lot from you Steven. Because you are so patient and have such a good sense of humour, you are easy to learn from. What I learn from you, I can also use for understanding some of the other residents here. For example, you remind me not to rush. You remind me that you can do a lot for yourself, if we let you. You remind me that inside that body, that does not want to obey you, lies a warm-hearted, fun-loving, caring person. When you try hard to tell me something and don't give up, you remind me that you have something important to say. I want to thank you very much for working so hard, for trying to talk so clearly to help me write this article so that other people can learn what it is like to have Huntington's disease. I know how tiring it is for you to communicate with me in such detail.

§

Education and Work in a Chronic Care Hospital

ALDA STEPRANS



Alda Steprans

Many people think of chronic care hospitals as places of disability, hopelessness and despair. I must admit that prior to working in one, my view of these places was similar. Getting to know the residents of such an institution has been one of the most enlightening experiences of my life. It has filled me with hope and amazement and a continued wonder at the ability of humans to learn.

Several years after I started working in a chronic care setting, I started my master's degree in Special Education at the Ontario Institute for Studies in Education (OISE) in Toronto. Many people thought it odd that I would select such an area for study. But the few years I had spent nursing severely disabled people taught me that most of them were learning — learning to live with their disabilities, learning to adapt to the challenges that nature had imposed

on them. Some of them learned very slowly and their behaviour changed over the course of many months. Others mastered things more quickly. At OISE, I hoped to learn how I, as a nurse, could help my clients to learn in a positive way. I hoped I would learn how I could help them to have a better quality of life and to take some control over their lives and over their health.

The people who come to live in a chronic care hospital are considered non-rehabilitable. Rehabilitation hospitals require quick success stories for their statistics. The fact is that rehabilitation can occur outside of a rehabilitation hospital. I could not help but notice that the first thing most residents of an institution do is learn the expectations and routines of the hospital. They become *institutionalized* — something that is vital to their own well-being and survival. How can caregivers make that process easier and give their residents more control?

Mr. S

I have often been awed at how hard many of the residents of this chronic care hospital work to learn new ways of helping their bodies function independently or to maintain the abilities they have. Mr. S., one of our residents who has multiple sclerosis, was unable to speak when he arrived at the hospital some 30 years ago. With physiotherapy and speech therapy, he slowly regained some muscle strength and learned techniques to control his breathing so that he could be understood again. Mr. S. still goes to therapy as much as he is able to. Without it, his muscle strength

decreases again and he becomes unable to express himself verbally. He works hard and it pays off. His arm and leg muscles are so weak that he can do little for himself. Thus, the ability to speak has given him a great deal of control over his life. At present, he can let others know what he needs, what he would like to eat, how he would like things done.

Mrs. M.

Mrs. M. had a stroke several years ago and her swallowing muscles were paralyzed. When she came to live at the hospital, she was fed through a tube in her stomach. Using a technique of ice cold stimulation at the back of her tongue, she slowly regained the ability to swallow. Presently the tube in her stomach is out and she has progressed from eating specially pureed food to enjoying French fries and other favourite foods once more. The right side of her body is also paralyzed, but she has learned to manipulate the food with the aid of special dishes and tools so that she can feed herself again. She has also learned to use a communication board to express herself when her own body language fails. Mrs. M. acquired so many skills that she was accepted to a rehabilitation hospital. We sadly said good-bye to her and were very surprised when, after a few months there, she decided to return to the chronic care hospital to live. She felt that at the rehabilitation hospital she was pushed to do things too quickly. She needed time! We are still hoping that with that time she will continue to achieve the goals she has set for herself.

Mr. B.

Mr. B. has Huntington's disease. He was very scared and aggressive when he came to live at the hospital. It took him several months to learn that we would do all we could not to hurt him, to take good care of him, to try to fill his days with events that are meaningful to him. He loves music and almost always has the radio on. On occasion, he feels lonely at night and cries. Often, when that happens, a favourite caretaker sits with him for a while. It is so good to see him smile! Most of his caretakers take great pride in being able to draw out those expressions of happiness.

Mr. G.

Mr. G. had suffered many years of severe heart disease when he arrived at the hospital. His elderly wife could no longer take care of him at home, even with community support. His chest pains were too erratic and frightening to them both. He was afraid of dying. Living at the hospital gave both him and his wife the energy to live and enjoy each day they had left together. She spent most of her time in the hospital, but could go home to rest in the evening, even sleep through the night. When Mr. G.'s time came to die, his family members stayed with him whenever they could. They would even sit with him through the night when he was

most frightened. His death was peaceful, with no pain. Staff were constantly there to address any fears, discomforts, concerns the whole family had. Together, we all learned to say good-bye to Mr. G.

We often forget that we are all capable of learning throughout our entire lives. We all learn at different speeds, for different reasons, in different ways. But what an exciting dimension learning adds to our lives. Since I have become more aware of the little ways people learn on a daily basis, nursing — caring for others — has been even more fascinating for me. Learning can provide hope and hope is central for a good quality of life.

§

CONTEXTS

We Don't Need No Mind Control

GEB VERBURG



Geb Verburg

Education

When this article began to grow in my head, and later, on my screen, I was almost embarrassed. I could not believe that I was capable of espousing the “red neck” ideas that you will find below. I assure you, however, that I am really writing out of a grave concern.

Regular readers will know that I usually write about some sad, bad, nasty, unpleasant, undesirable state of affairs, or situation and then find something positive or some possible way out of a bad spot. Well, I almost could not find anything positive to say about the direction in which I perceive the education of our children is and has been moving.

The sources of my information are my children, both in high school now, especially my daughter who has gone through a large number of different schools before she could find a place where she felt she could learn what she wanted to learn. My second source is friends who happen to be secondary and high school teachers in the public system. Not the most objective sources, I know, but they are in the system.

Concerns

I just have that dreadful sense that kids are learning less, or differently, and it certainly looks as if they are learning more reluctantly and less thoroughly than we did. This entire sentence is of course a tell-tale signal that I am getting older and I will not deny that. You might now expect me to embark on a rant aimed at new technology, the laxity of “The System”, present-day politics or other, more contentious issues. I will not. I really believe that there is much to be concerned about in the education of our children (and where applicable, grandchildren).

My daughter's spelling was excellent when she finished grade 6 and has been slowly going down from that point. Her vocabulary is and has from early on been very

large and she writes very well. Just her flawless spelling has gone. My son's spelling and punctuation left much to be desired from grade one onwards. Yet every year he gets, what I consider euphemistically, report cards that tell us that he is operating at grade level.

Arithmetic and mathematics seem to be other topics that have suffered. I know that I spent one vacation driving down to Florida rehearsing times tables with my son. I am very happy that he is now quite competent and skilled in arithmetic and likes mathematics, no thanks to that trip no doubt. Miriam, on the other hand, became comfortable and skilled with numbers after she had worked at a waiting job for a season.

When, during the annual teacher interviews, I sit and listen to teachers explain that they are teaching "problem solving" and "independent thinking" I shudder. What a wonderful goals but what an impossible task. I would much rather, teachers would decide to teach children how to read, write, and do arithmetic including mental arithmetic. For if they did, children might be capable of learning independently and could maybe even learn to think creatively. I keep thinking that if students were to acquire a solid base of ordinary facts, events in history, cultures in the world, and nations on a globe then their creative thinking would have a basis in reality which I think would be exceedingly important.

Working

Again a story from home. Last year my daughter relayed an incident that happened in her classroom. She was telling me how she was enjoying a class and felt sorry for her teacher who was asking students in the class to respond to her (the teacher's) questions. The questions were not

difficult but nobody answered them. Miriam knew the answer but, as she went on to say, could not respond because she had already done so once before that morning. I asked why and she replied that in her class anyone who responded more than once a day was considered a nerd and excluded from social contact. I was indignant and disappointed and I still am because I have learned that this attitude is not unusual in schools in Toronto.

A teacher friend told me that some of her students regularly "forget" their books, notes, pencils or any other thing that might give them an excuse to either annoy the teacher, get sent to the principal's office, or get a chance to go to their locker. They use any of these events to completely skip class. For me this means that we are wasting the teachers' time, the time of the students who want to learn, taxpayers' money, and also the time of the teenagers who are in the school system and who are not willing or choose not to learn.

Rather than automatically promote or pass these students to the next grade level, I think we should find a real alternative for them. They are stuck, as much as the teachers whose time is also wasted. If we don't do anything for these students, in 10 years we will have far too many young adults who have no knowledge, no skills and no ability to learn, and who will, therefore, be excluded from many forms of economic and vocational participation in their society. One could say that they are doing it to themselves. I am not sure I believe that. And anyway, it is irrelevant. It is a shame and will be an economic millstone to have so many minds simply go to pot because it is not "cool" to know answers to questions or to learn.

Why are we in this situation?

What ails the education of our children? Is it the system, the teachers, the kids, or the parents? Or could it be the lack of funding, the lack of interest, the low priority of education in our society? What about the decline of learning and learned institutions? Has education and learning lost its value, message, meaning? Are the kids lazy? Or the teachers? Or have we created a system that encourages lack of performance and punishes zeal? Underfunding? Overfunding? Lack of discipline? ...

I could continue to list possible reasons for what I perceive to be the decline of our educational system or process or enterprise. The remarkable and scary thing is that each and every one of these reasons has probably been brought forward by someone in the last five years with more than a little justification. Has that solved anything? No! Has it changed anything? No!! Has it helped us understand what is really wrong with education? No!!!

How can affluent countries like the US and Canada have such high illiteracy rates? Why do so many kids not want to learn? Or, why is it so easy to dissuade kids from trying to learn? Why are the peer pressures in the public educational system so overwhelmingly directed away from learning?

Schools and teachers in the system are faced with a number of impossible options. They are not able to fail a person for not performing at grade level. They do not have standardized tests against which to compare the performance of every student. Nor are they able to adequately punish a student for non-performance of work, or reward a student for exceptional performance.

They are not able to expel a student who obviously does not want to learn, and yet are faced every day with a classroom of kids whose sole goal is to annoy the teacher, obstruct the system and learn nothing. *You see what I meant, when I warned you about "red-neck" ideas.*

Of course, many other interpretations are possible. Furthermore, there are still schools where children go to learn and actually do so! Moreover, not all kids are as bad as I pictured. And, notwithstanding all of the above ... Yes yes yes. There may still be time. But I think we should get cracking at the identification of alternative solutions or, maybe first, find some truly alternative problems.

Alternatives

First let me pick up where I left my kids. Yes, their spelling (or as I might as easily say "there spelling") needs help and gets it of course from the spell checkers on their workstations. Their mental arithmetic is not too hot and they rarely solve sums on paper. But they know how to use a calculator and how to find the calculator function on any computer, or how to compose Excel functions. This is a different kind of dependence which is new and somewhat scary to me. But not really because, I'm pretty sure, that whatever happens, computers are not going to disappear out of my children's lives. Of course, the machines will gradually vanish from our sight and start to inhabit our walls, our pockets, the lining of our clothes or, ethereally, occupy any room or space that we inhabit (scary too, that). But they will always be there to spellcheck (write) our letters or communicate our thoughts in ways that other computers can decode into speech, writing, images, or thoughts. So I have not actually worried too

much about the lack of spelling proficiencies. They will take care of themselves. I am also less worried about number skills, including the memorization of times tables, having seen that they can still handle number problems.

My kids are highly verbal, and so are their peers including the ones who are refusing to answer more than one geography question a day. My kids are very computer literate and can negotiate the web better than I can. They illustrate most of their written assignments with pictures scavenged from relevant websites, which also provide much of the content.

I just have that dreadful sense that kids are learning less, or differently, and it certainly looks as if they are learning more reluctantly and less thoroughly than we did.

You know where I'm heading already. I think that the most important thing wrong with education today is that it is a long way behind where the kids are. They have leapt ahead into the information age and have left a sluggish and overly conservative, too heavily literate, or literacy dependent system of instruction behind. Perhaps they have done this because they recognize its inadequacy, its outdatedness. I am inclined to believe that our kids sense that what the schools are still teaching has lost most of its relevance for tomorrow's world, and much of it for today's. Maybe kids and artists do have that special link to the future that we, ploddingly

sequential and literate adults can barely grasp. If we do, it is much later when we finally can symbolize it in our cumbersome words.

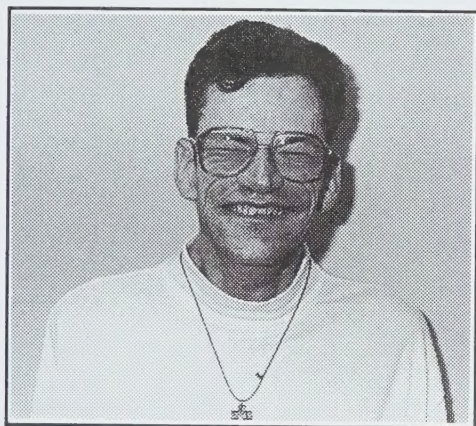
If my assessment is correct, then it is a much less depressing picture. It does not mean that today's children are bad or lazy or incompetent. It does not diminish the shame of having large number of teenagers sit and obfuscate a doomed system. It is all the more wasteful, because we could already be trying to let them define what it is they think they will need for the future. We probably could speed up those trials and, in the process, learn what will be the essence of future information curricula.

But aside from that, what does this mean for the "typical" AAC kid? What does it mean for the child who has grown up using a computer to become verbal, who used a computer to learn in school, who by means of a modem could talk with other kids just like themselves? What does this potential change in education mean for nonspeaking children? First, that they better make sure that they are as verbal as their peers (by this I mean that their vocabularies, active or passive, are as big as those of their peers). They also should make sure that they are as computer literate as their peers. In fact because of their reliance on technology, most are probably ahead of their peers in computer literacy. They also need to learn to manipulate, find, and use information as well as their non-disabled peers are learning to do. I would expect that nonspeaking kids could more than hold their ground with a little help from their speech-language pathologists, parents, teachers, therapists, other professionals and friends.

§

The Mind-sets of Employment

PAUL MARSHALL



Paul Marshall

Throughout history, the view of working and providing for ourselves is almost a creed of living. People seem to be measured by what they do throughout life. This, no doubt, puts a huge weight on each one of us to conform to this social norm. As you think about it, all of life has something to do with doing something. We spend many years from our childhood to early adulthood getting the basic skills to be capable to of (a) looking after ourselves and, in many cases, our offspring and, (b) being a provider to our community. This, in a nutshell, defines a form of a lifestyle.

As many of you already know from reading my columns, I grew up in a farming lifestyle where we all had to pull together to share in the daily responsibilities. I couldn't do the jobs that my brothers could do for our parents. But I had other duties that I had to do in order to be a working member of a farm family. As a member of a working society, we all have our responsibilities to be a taker and a giver. We each have different skills and capabilities.

When we realize these skills and capabilities, we can share globally in the world of working. We get so wrapped up in living a life with the responsibilities of caring for our families that we just don't realize that in doing this, we are also caring for the larger world around. When we work, we are giving to the society of which we are a part. This is through jobs that maintain services, develop products, provide medical and protection services, teaching, and so forth. We also are paying taxes that hopefully will go to maintain and create better lifestyles for the general population.

**Real employment is living life
the best that we can and
offering our own special skills
to the world around us.**

But with the option of the home office as an alternative way of being employed, we are seeing a big difference in people's employment environment today. Not too many years ago, the norm was getting in cars or on buses and going to an office where we put in our eight straight hours of work. Now, some of us can have the option of working at home. This is a vital opening for countless employment options for anybody with a disability. I know that for myself for example, what I do in AAC and in research fields is done largely via my home computer. On the days that I work at home, I don't have to worry about transportation, weather, the busy roads, or being understood if something goes wrong. When I work at home, I am in my own environment, where I

have all of the resources I need around me. Sometimes I even feel that I can get more work done when I am at home. Don't get me wrong. I need the social interaction with my peers that I get on the days that I "go to work".

I feel that I am very blessed to be capable of and allowed to do the work that I do at home as well as outside of my home. In the eyes of society however, what I do may not be viewed as *employment*. After all, what I do does not pay enough to support me. Because I receive a disability cheque each month however, I am able to spend and donate most of my time to doing things to help the world around me.

This brings me to my big question: *What is employment?* One meaning of the word is "the act of engaging a person for work". To me, however, employment is more than getting a pay cheque every two weeks. Granted because I get a disability check, I am very thankful that I don't have to depend on maintaining a regular job to live. Just because I have a disability however, does not mean that I have an option of sitting back and doing nothing with my life. I have been given skills. If I don't use them, I am not living life fully.

I don't care what or how bad a disability people have. If we can only smile and make someone smile back, that is employment and that is our job. A smile can't be measured by a pay cheque. Let's not get fooled into thinking employment is only for the strong and healthy. Real employment is living life the best that we can and offering our own special skills to the world around us.

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PAUL MARSHALL

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